

May 13, 2005. Toronto Star

'We got our child's diagnosis from her death'

When 9-month-old Jenna got sick in November 2002, her mother Tammy hoped she wasn't getting the miserable flu that had felled her son Justin, 2, the week before.

But the next day, her pediatrician confirmed her fears, told her to give the baby Tylenol for the fever and to "keep pushing fluids."

But Clark didn't get much chance to do that. At 6:30 the next morning, the beautiful red-haired baby died in her mother's arms as her husband frantically called 911.

A month later, Clark heard from the coroner's office that her baby had died from MCAD, a metabolic disorder she had never heard of.

When she was told her baby could have been tested for it at birth, "I was outraged, shocked to learn that something as common sense as this could go so wrong," she says.

Now Clark, who lives in the Ottawa area, is trying to organize other parents to get the system changed through a fledgling organization called Save Babies Canada.

When she asked the Ministry of Health what it was going to do about newborn screening, she was told that the ministry was working on it, Clark says.

"That's great for them to say but we got our child's diagnosis from her death because the coroner's office got involved. How can it be justified that children are screened when they're dead, not when they're newly born? What use is that?"

elaine carey, medical reporter